

**WHO Symposium on Meaningful Engagement of people living with NCDs,
mental health and neurological conditions**
*in the lead up and delivery of the 4th High-level Meeting of the United Nations
General Assembly on the Prevention and Control of NCDs*

Terms of Reference

The WHO Symposium on Meaningful Engagement of people living with noncommunicable diseases (NCDs), mental health and neurological conditions (hereon referred to as the WHO Symposium on Meaningful Engagement) will serve as a platform to advance the meaningful engagement and greater involvement of people living with NCDs, mental health and neurological conditions in the preparatory process for the 4th High-level Meeting of the United Nations General Assembly on the Prevention and Control of on NCDs in 2025 (hereon referred to as the 4HLM on NCDs). The WHO Symposium on Meaningful Engagement will take the form of at least one annual meeting to convene, formally recognize and leverage the knowledge and expertise of people with lived experience to co-create and co-implement strategies for the operationalization of meaningful engagement of people living with (PLW) in the preparatory process for the 4HLM on NCDs, in order to enhance NCD policies, programmes, and services that are responsive, equitable, holistic, and contextually appropriate.

Rationale

To amplify the voices and leverage the expertise of people living with NCDs, mental health and neurological conditions (herby referred to as individuals with lived experience) as essential co-creators of the preparatory process for the 4HLM on NCDs, the WHO Symposium on Meaningful Engagement will serve as a platform to convene individuals with lived experience, and will provide opportunities for knowledge exchange and collaboration, multisectoral and interdisciplinary networking and capacity building, and fostering innovative approaches and partnerships. The Symposium also intends to facilitate integration between the global NCD community and major public health and policy agendas toward accelerated and integrated responses to achieve Sustainable Development Goal (SDG) 3.4 (by 2030, to reduce by one third premature mortality from NCDs through prevention and treatment and promote mental health and well-being).

Building on the progress made at the 3rd High-Level Meeting of the United Nations General Assembly on NCDs in 2018 and to garner further success in the lead up to, during, and following the 4HLM on NCDs, the WHO Symposium on Meaningful Engagement will facilitate building strategic alliances and coalitions between individuals with lived experience and WHO and its Member States. This will also support and complement the wider global NCD community and stakeholders in public health and policy sectors to enhance awareness and support co-creation of bold action for the NCD, mental health and neurological health response, in the preparatory process at national and global level leading up to 2025. It will draw upon the success and lessons learned of global lived experience movements such as HIV/AIDS, Disability, Universal Health Coverage (UHC), Dementia, Healthy Ageing and Mental Health, which accelerated meaningful and sustainable policy changes through strategic multi-sectoral collaboration and partnerships, robust evidence-based approaches, positive narrative change, awareness raising, and advocacy through a lens of meaningful engagement.

Objectives

Objective 1: Support the preparatory process for the 4HLM on NCDs by building on the progress made during the 3rd High-Level Meeting on NCDs in 2018, in particular by identifying and conducting

advocacy activities that increase support to WHO public health objectives, raise awareness of meaningful engagement and catalyze greater involvement of individuals with lived experience. To achieve this, the WHO Symposium on Meaningful Engagement will:

- Conduct a stakeholder mapping to identify in detail the voices of those with lived experience at risk of being left behind and of groups that are marginalized, who have the most to offer with the fewest opportunities to contribute;
- Explore alignment and integration with other lived experience communities to amplify existing and new advocacy activities;
- Develop a global advocacy strategy for meaningful engagement and greater involvement of individuals with lived experience for the 4HLM on NCDs;
- Promote and disseminate information and resources aligned with WHO recommendations on meaningful engagement and greater involvement of individuals with lived experience, including contextualizing and supporting action at country level;
- Promote and support, when and where relevant, WHO public health messages and as appropriate events on meaningful engagement and greater involvement of individuals with lived experience at global and regional level.

Objective 2: Strengthen knowledge exchange and collaboration between individuals with lived experience, WHO and WHO Member States to support co-creation and co-implementation of actions to support the NCD, mental and neurological health response in the lead up to, during, and after the 4HLM on NCDs. To achieve this, the WHO Symposium on Meaningful Engagement will:

- Provide a platform for dialogue between individuals with lived experience, WHO, WHO Member States and other relevant stakeholders;
- Support the co-creation and co-implementation of WHO outputs in support of the 4HLM on NCDs including, but not limited to, technical products, global initiatives, events, dialogues and forums, as relevant;
- Strengthen and increase communication between the participants of the WHO Symposium on Meaningful Engagement and WHO across the three levels, and other relevant stakeholders.

Objective 3: Support the evidence-base that underpins the interlinkages between the systemic determinants and risk factors for NCDs and other global crises and strengthen coalition-building and coherence between individuals with lived experience and other relevant stakeholders across the NCD-related public health and policy agendas. To achieve this, the WHO Symposium on Meaningful Engagement will:

- Ensure participation from individuals with lived experience from a broad range of strategic health topics which are and can be linked to HLM4 and across agendas;
- Develop cross-cutting thematic workstreams across global health topics and policy issues that aim to strengthen buy-in, coherence and support from stakeholders across sectors;
- Identify outputs that can be leveraged at major annual conferences or meetings of UN specialized agencies and other partner organizations in the lead up to, during, and after the 4HLM on NCDs.

Format

Three events supporting the WHO Symposium on Meaningful Engagement will be held in 2024 and 2025 with a view to disseminate outputs and key findings across all relevant milestones in the lead up to the 4HLM on NCDs, including at the World Health Assembly (WHA) and United Nations General Assembly (UNGA) side events.

Each event will take place over two to three days. Each event will be co-created and co-implemented with leadership from the lived experience community, according to the urgent cross-cutting global health and policy issues affecting individuals with lived experience that should shape the transformative NCD agenda over the next decade discussed and adopted at the 4HLM on NCDs.

The WHO Secretariat will work with the Symposium Steering Committee to co-create and co-implement the agenda and session formats and ensure that the Symposium is adhering to the principles and enablers of the WHO Framework on Meaningful Engagement. Symposium sessions will be fully participatory in nature, with shared planning and decision-making responsibilities between people with lived experience and WHO, with the goal of generating, developing, and communicating recommendations on how to operationalize the meaningful engagement of individuals with lived experience into the outcome document of the 4HLM on NCDs.

Governance

The WHO Symposium on Meaningful Engagement is led by the WHO Secretariat, supported by an informal Steering Committee and implemented through its full participant network. The governance and structure of the WHO Symposium on Meaningful Engagement is designed to facilitate coordination of activities, to ensure activities align with the overall mission and objectives of the WHO, the WHO Symposium on Meaningful Engagement, and to preclude influences of individual or organization-specific agendas.

The Secretariat

WHO serves as the Secretariat of the WHO Symposium on Meaningful Engagement.

The role of the Secretariat is to oversee the day-to-day management of the work of the WHO Symposium on Meaningful Engagement, including coordination of discussions across stakeholders on priorities and gaps, event and priority planning, and overall responsibility for the outputs, along with administration and budget management.

More specifically, key responsibilities of the Secretariat are as follows:

- Chair the Steering Committee meetings;
- Serves as the interface between the WHO Symposium on Meaningful Engagement's Steering Committee, and WHO, in particular ensuring alignment and support to WHO's NCD and NCD-related programmes;
- Serves as the interface between the WHO Symposium on Meaningful Engagement and its participants;
- Selects and manages participants and the Steering Committee in line with WHO rules and policies;
- Coordinates the development, implementation and maintenance of the WHO Symposium on Meaningful Engagement in consultation with the Steering Committee;

- Oversee implementation of the TORs of the WHO Symposium on Meaningful Engagement in collaboration with the Steering Committee;
- Monitor and evaluate activities and processes of the WHO Symposium on Meaningful Engagement making amendments as necessary, in consultation with the Steering Committee, to optimize its functioning and impact;
- Coordinate correspondence with participants, as required, to facilitate participation and collaboration of all members;
- Coordinate the annual events of the WHO Symposium on Meaningful Engagement in collaboration with the Steering Committee, including development of relevant documentation (e.g. agenda, pre- and post-surveys, etc.) and logistical support;
- Develop a central repository for the WHO Symposium on Meaningful Engagement to house all relevant documents and resources;
- Develop and regularly update a website for the WHO Symposium on Meaningful Engagement (hosted by WHO).

The Secretariat's support will be provided in accordance with WHO's rules, regulations, policies and procedures. The Secretariat reserves the right to contest recommendations or activities which it determines gives rise to undue financial, legal, or reputational liability or is contrary to WHO policies, regulations, and procedures.

Co-creation and co-implementation of the WHO Symposium

There will be an open invitation to submit applications for two opportunities for the co-creation and co-implementation of the WHO Symposium on Meaningful Engagement:

- **Informal advisory support**
 - Could comprise of up to 20-30+ participants with lived experience in NCDs, mental health, and neurological conditions who provide voluntary feedback, as available and interested, into the co-development of the events supporting the WHO Symposium on Meaningful Engagement.
 - The selection process will be an open call for expressions of interest and will strive for balanced representation with respect to gender, age, geographical area, income setting and lived experience.
 - Feedback will be solicited through an email listserv and/or on the Knowledge Action Portal (KAP), including opportunities to provide feedback over email, KAP, one-on-one conversations, or informal feedback sessions with the Secretariat.
- **Steering Committee**
 - WHO will select a Steering Committee for the WHO Symposium on Meaningful Engagement of up to 6-8 members representing a balance of lived experience across gender, age, geographical area, income setting, type of lived experience, and expertise. Steering Committee members will be engaged on a part-time basis (~8 hours/month) by WHO through a formal agreement to support the Secretariat in co-creating and co-implementing the WHO Symposium on Meaningful Engagement and its events.
 - Steering Committee members will be invited and selected based on interest, availability, and relevant expertise in development of participatory activities.

- The Symposium Steering Committee will conduct its work through regular monthly meetings, collaboration on shared deliverables, and any other feedback and communication mechanisms as needed.
- The Steering Committee will be chaired by WHO, with the work plan and deliverables supported by 2-3 WHO representatives, and its decisions will be made through consensus.

Key responsibilities of the Steering Committee are as follows:

- Provide strategic guidance for the operative work of the WHO Symposium on Meaningful Engagement;
- Jointly coordinate with the Secretariat on the definition and prioritization of relevant outputs of the WHO Symposium on Meaningful Engagement, including development of relevant documentation, dissemination of materials, and other logistical support;
- Support the monitoring and evaluation activities and processes of the WHO Symposium on Meaningful Engagement.

Expected outputs

- Broad range of activities and outputs in the lead up to the UNGA UN HLM4, including Symposium led contributions and involvement in inter-organizational dialogues or events including those related to the 4HLM on NCDs, WHA, and other WHO milestones on its [proposed 'road to 2025'](#), through:
 - Strengthened coalitions between individuals with lived experience and other relevant stakeholders across the public health and policy agendas to enhance strategic collective action toward achieving SDG Goal 3.4 by 2030.
 - Co-creation of a global advocacy strategy for the meaningful engagement of individuals with lived experience throughout the HLM preparatory process, with a focus on prioritizing the most marginalized voices in addressing social, economic, commercial and environmental determinants of NCDs, mental health, neurological conditions, and other relevant global health challenges.
 - Dedicated open access webpage on the [WHO Knowledge Action Portal on NCDs](#) to contain commentaries, reports, case studies, blog posts and other media and publications produced by participants of the WHO Symposium on Meaningful Engagement, as approved by Secretariat.

Participation in WHO Symposium on Meaningful Engagement

The WHO Symposium on Meaningful Engagement will call for participation to support its agreed events. Participation in the WHO Symposium on Meaningful Engagement is open to representatives who identify as individuals with lived experience of NCDs¹ or comorbidities or identifies as a family member and/or caregiver for individuals with lived experience. Participation will be encouraged from individuals with lived experience from other areas that could provide integrated attention to co-morbidities with NCDs, such as maternal and child health, disabilities, COVID-19, HIV/AIDS, tuberculosis, and other related communicable diseases. Whilst the participants would be representing themselves on an individual basis, they will also be required to disclose any professional affiliations, as per WHO due diligence procedures.

¹ Including (but not limited) to cardiovascular diseases, cancer, diabetes, mental health conditions and neurological disorders, and respiratory illnesses.

All individuals seeking to participate in the WHO Symposium on Meaningful Engagement must meet the following criteria:

- The individual should contribute to the advancement of public health and to the objectives, vision and goal of the WHO Symposium on Meaningful Engagement and demonstrate support for the meaningful engagement and greater involvement of people living with NCDs, and mental health and neurological conditions;
- The individual should respect the intergovernmental nature of WHO and the decision-making authority of Member States as set out in the WHO Constitution;
- If an individual is applying and is professionally linked to a non-State actor, the individual is required to provide an up-to-date Declaration of Interest (DOI) form.

Participants of the WHO Symposium on Meaningful Engagement are expected to act in the best interest of public health in alignment with the goals of the Symposium on Meaningful Engagement, the WHO Framework on Meaningful Engagement of People Living with NCDs and Mental Health and Neurological Conditions, and WHO policies and procedures, including its Framework of engagement with non-State actors.

Participants should not engage with the tobacco or arms industry, nor with non-State actors that work to further the interests of these industries. Participants should not be representing, or perceived to be representing commercial entities that could undermine public health interests.

Applications for participation in the WHO Symposium on Meaningful Engagement

A standardized form and online application process will be developed by the Secretariat. All applications will be approved by the WHO Secretariat. Participation approval will be based on an assessment, due diligence process, and review of submitted documents, in accordance with the eligibility criteria and in accordance with WHO's rules and policies. Participation will only apply to the specific event applied for. Applicants will be notified of their participation approval (or otherwise) by the WHO Secretariat.

I. Terms of Participation

The WHO Secretariat has the right to reconsider participation of approved participants or of Steering Committee members at any time, in cases where participants: (a) no longer subscribe or adhere to the TORs, goals, and/or guiding principles of the WHO Symposium on Meaningful Engagement; and/or (b) engages in activities that are not compatible with WHO's policies and principles.

II. Communications

Participants must ensure that the work of the WHO Symposium on Meaningful Engagement is not misrepresented. Public statements by participants representing themselves or organizations outside of WHO throughout the activities of the WHO Symposium on Meaningful Engagement shall contain appropriate disclaimers, including that the content does not reflect the views of WHO or of all the participants of the WHO Symposium on Meaningful Engagement.

The WHO Secretariat will set, where required, relevant guidelines for shared use of logos or visual assets specific to the WHO Symposium on Meaningful Engagement, in collaboration with the Steering Committee.

The WHO Symposium on Meaningful Engagement will have a webpage that is housed within WHO's domain and managed by the WHO Secretariat. The webpage will include a list of Steering Committee members, individuals providing informal advisory support, and participants, subject to their consent.

III. Finance

The Secretariat supports all related day to day operations of the WHO Symposium on Meaningful Engagement, including support to the Steering Committee.

Participants will be responsible for their own expenses in relation to participation in activities and events of the WHO Symposium on Meaningful Engagement. However, WHO is committed to ensuring that virtual and in-person activities are as accessible as possible, with due consideration to geographic region and income setting, with special consideration to opportunities to support participants from low-income settings or marginalized backgrounds. Participants may also receive third party funding to support participation in activities of the WHO Symposium on Meaningful Engagement, which must be disclosed to the Secretariat.

IV. Amendments

These Terms of Reference may be amended by WHO in consultation with the Steering Committee.